

# Role of Pediatric and Internist Rheumatologists in Treating Children With Rheumatic Diseases

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**ABSTRACT.** *Objective.* To quantify and describe the role of internist and pediatric rheumatologists in the care of children with rheumatic diseases and identify factors associated with internist rheumatologists' willingness to treat children.

*Methods.* We surveyed physician members of the American College of Rheumatology who currently practice in California ( $n = 589$ ). Bivariate and logit analyses were used to examine the effects of training, provider, practice, and distance to the nearest pediatric rheumatologist on the likelihood that an internist rheumatologist treated children.

*Results.* Our effective response rate was 51%. More than one third of internist rheumatologists who practice in California reported treating pediatric patients. On average, internist rheumatologists who treated children saw 3.1 patients younger than 18 years weekly; half of these patients were 16 and 17 years of age. In logistic regression analysis, internist rheumatologists who treat pediatric patients were significantly more likely to practice in a multispecialty clinic (adjusted odds ratio: 3.5; 95% confidence interval: 1.9–9.7) and to live >50 miles from a pediatric rheumatologist (adjusted odds ratio: 6.8; 95% confidence interval: 2.1–22.7). In aggregate, we estimate that pediatric rheumatologists and internist rheumatologists provide care to 550 and 419 patients younger than 18 years per week, respectively.

*Conclusions.* A substantial number of California internist rheumatologists are involved in the care of children, especially adolescents. The heavy involvement of internist rheumatologists in the care of children suggests that additional pediatric rheumatologists may be needed in select areas. Our findings have important implications for the size and distribution of the pediatric rheumatology workforce, the content of fellowship training for internist rheumatologists, and future studies of the relative quality of pediatric rheumatology care offered by internist rheumatologists. Furthermore, the role of internist subspecialists in caring for children with other chronic illness should be assessed. *Pediatrics* 2004;113:e173–e181. URL: <http://www.pediatrics.org/cgi/content/full/113/3/e173>; *health manpower, rheumatic diseases, physician practice patterns, rheumatology, chronic conditions.*

ABBREVIATIONS. AAP, American Academy of Pediatrics; JRA, Juvenile Rheumatoid Arthritis; ACR, American College of Rheumatology.

Access to pediatric subspecialty care has been cited as one of the American Academy of Pediatrics' (AAP) top 8 concerns,<sup>1</sup> yet access to pediatric specialists has not been widely investigated. The small number of pediatric subspecialists and their tendency to practice in academic medical centers creates a geographic distribution of providers that limits access for a segment of the pediatric population at risk. Despite this known maldistribution, the adequacy of the current supply of pediatric subspecialists has not been established. The reason for the lack of inquiry in this area is not clear, but it may relate to an assumption that there exists an oversupply of both adult and pediatric specialists and subspecialists.

Pediatric rheumatology provides a sentinel example of limited availability of pediatric specialty care. One of the smallest subspecialties in the United States, only 174 board-certified pediatric rheumatologists practice in the United States<sup>2</sup> and an additional 50 physicians describe themselves as pediatric rheumatologists.<sup>3</sup> Although pediatric rheumatologists have been specifically trained to treat the complex, severe, and sometimes life-threatening rheumatic diseases of childhood, previous studies suggest that internist rheumatologists play a prominent role in the care of children with these diseases.<sup>4–6</sup> A 2000 report showed that one third of children with a known rheumatic disease received their care from an internist rheumatologist.<sup>7</sup> Likewise, a study of Medicaid children eligible for supplemental security income found that only 18% of children with juvenile rheumatoid arthritis (JRA) saw a pediatric subspecialist and 30% saw an internist subspecialist.<sup>6</sup>

Pediatric rheumatic diseases affect ~285 000 children in the United States.<sup>8</sup> The most common form of juvenile arthritis, JRA, affects 148 to 167 children per 100 000.<sup>9</sup> The overall prevalence of pediatric rheumatic disease is relatively low; however, collectively these conditions are among the most common chronic illnesses of childhood<sup>10,11</sup> and involve considerable disease burden and disability. Pediatric rheumatic diseases require frequent and ongoing medical care, including physician visits, laboratory work, infusion therapy, and physical and occupational therapy. Thus, long travel distances between the patient and the caregiver can impede continuity

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of care and access to important ancillary health care services.

A recent study of physician members of the American College of Rheumatology (ACR) found that ~50% of the population younger than 18 years in the United States lives 50 or more miles from a pediatric rheumatologist.<sup>3</sup> Of these, more than half live 100 or more miles from such a provider. Notably, this study found that distance to pediatric rheumatology care was significantly related to internist rheumatologists' involvement in the care of children, controlling for a variety of other factors. Another study found that internist rheumatologists who reported treating children lived a significantly greater mean distance from a pediatric rheumatology referral center than those who referred children (101 vs 21 miles), and distance was the most frequently reported reason (66%) for not referring a child to a pediatric rheumatologist.<sup>4</sup> This study also found that exposure to pediatric rheumatology during adult rheumatology fellowship was associated with greater likelihood of internist rheumatologists' treating pediatric patients.<sup>4</sup>

To quantify the role of internist and pediatric rheumatologists in the care of children with rheumatic diseases and to identify factors associated with internist rheumatologists' willingness to treat children, we surveyed all California physician members of the ACR. Using our survey results, we explored the role of internist rheumatologists in treating children and the relationship between training, professional, personal, and health system characteristics and internist rheumatologists' involvement in the care of children. We also estimated the number of patients who are younger than 18 years and treated by pediatric and internist rheumatologists. This study of pediatric rheumatology serves as a case study of the implications of the size and distribution of the current pediatric subspecialty workforce and the current role of internist subspecialists in the care of children.

## METHODS

### Data Source

In April 2002, we surveyed all physician members of the ACR who were listed as practicing in California ( $n = 589$ ). Follow-up questionnaires were sent to nonrespondents every 4 to 6 weeks. The fourth and final mailing was sent in November 2002. We made every effort to enhance response rate, including use of business reply envelopes, 4 mailings, use of a prize drawing as an incentive, and aggressively finding physicians whose ACR address was incorrect.

### Instrument

The 10-page survey included questions on residency and fellowship characteristics, professional activities and setting, and personal characteristics. In addition, internist and pediatric rheumatologists who are involved in the care of children were asked to complete a section on the age and diagnoses of their pediatric patients, their comfort in treating a variety of pediatric rheumatic conditions, factors that influence their willingness to treat children, and receptivity to collaboration with pediatric rheumatologists. For rheumatologists who are not involved in the care of pediatric patients, the survey included questions about their reasons for not treating children as well as their interest in treating children if provided with additional training or pediatric rheumatology support. The Institutional Review Board of the University of North Carolina School of Public Health approved the study.

### Number of Patients Treated

All respondents were asked to indicate separately the number of new and follow-up patients that they saw weekly for 2 age groups: patients younger than 18 years and those 18 and older. When a respondent indicated a range for any of these groups, the number was coded to the middle of the range (eg, a provider who reported 30–50 patients under 18 seen in a week was coded as seeing 40). When respondents listed the number as below a certain value, it was coded to the listed value (eg, <1 was coded as 1). Sensitivity analyses were also performed by coding to the lowest end of the range or to 0 when a “less than” sign was used.

### Involvement in the Care of Children

Although we had data on the number of patients who were younger than 18 years and seen by respondents, we wished to distinguish providers who perceived themselves as treating pediatric patients from those who likely treat a small number of older adolescents but do not perceive themselves as providers of pediatric rheumatologic care. We used the response to the question, “Do you treat pediatric rheumatology patients?” and data on residency and fellowship to classify respondents into 1 of 3 groups. Respondents who reported that they completed a pediatric residency and/or a pediatric rheumatology fellowship and reported that they treated pediatric rheumatology patients were considered to be pediatric rheumatologists. Among internist rheumatologists, those who reported that they did treat pediatric rheumatology patients were considered to be internist rheumatologists involved in the care of children. All other internist rheumatologists were classified as internist rheumatologists only.

### Exposure to Pediatric Rheumatology During Fellowship

Respondents were asked to characterize their exposure to pediatric rheumatology during their fellowship training as none, minimal (ie, <12 half-day clinics or equivalent), moderate (13–24 half-day classes or the equivalent), extensive (>24 half-day clinics), or “other.” For those who selected other, respondents were asked to provide more information about their exposure. We reclassified “other” to 1 of the other 4 classes whenever possible (eg, spending a year at a JRA center overseas was coded to extensive).

### Percentage of Time in Professional Activities

We used physician self-report to estimate the percentage of time spent in each of the following professional activities: rheumatology patient care, primary care, research, teaching, and other. For academic physicians, we asked for the number of hours per week spent in each of these activities for both “on-service” and “off-service” periods. The percentage of time spent in each activity was calculated using the reported number of hours spent in each arena as a percentage of the total number of hours worked per week. For academic physicians, we used the number of hours in each activity during off-service periods. When off-service hours were not reported, we used on-service values. We summed the percentage of time in research, teaching, and other activities to generate a variable for the percentage of time in professional activities other than patient care. To prevent loss of observations from the logistic regression analyses, we imputed the value of the percentage of time in nonpatient care activities for a small percentage of cases (4.8%).

### Distance to the Nearest Pediatric Rheumatologist

In addition to the survey data, we used data from a previous study to measure the distance between each respondent's zip code and the nearest pediatric rheumatologist. These data were generated using ACR membership data and county latitude and longitude data from the Bureau of Health Professions Area Resource File.<sup>12</sup> Detailed data on this measure and its construction are reported elsewhere.<sup>3</sup>

### Data Analysis

#### *Responders Versus Nonresponders*

To compare responders and nonresponders, we used data from the ACR membership file. As described elsewhere,<sup>3</sup> we classified all ACR members into 3 categories: 1) internist rheumatologists

who treat adult patients only, 2) pediatric-only providers who treat primarily pediatric patients, and 3) internist rheumatologists who also treat pediatric patients. We compared respondents and nonrespondents with regard to their involvement in the care of children according to the ACR file, primary practice location, proximity to a pediatric rheumatologist, and their professional activities.

#### *Characteristics of Pediatric and Internist Rheumatologists*

We performed bivariate analyses of the personal, professional, and training characteristics of pediatric and internist rheumatologists. For categorical data, we used  $\chi^2$  analyses or Fisher exact tests for comparison with cell sizes  $<5$ . For the limited number of continuous variables, we used 2-sided *t* tests for normally distributed variables and Wilcoxon rank sums for nonnormally distributed variables. We considered continuous variables with Shapiro-Wilks test values of  $<.05$  to be nonnormally distributed. Bivariate analyses were also used to compare pediatric rheumatologists and internist rheumatologists involved in the care of children.

#### *Internist Rheumatologists' Involvement in the Care of Children*

Using the statistical analyses described above, we compared internist rheumatologists who treat children and those who treat adults only. Mindful of our small sample size, we crafted a parsimonious logistic regression model to examine determinants of internist rheumatologist involvement in the care of children. For this logistic regression analysis, our dependent variable of interest was self-reported involvement in the care of pediatric patients, and we restricted our analysis to internist rheumatologists.

#### *Number of Patients Seen by Provider Group*

To estimate the total number of children treated by each group of providers, we aggregated the number of new and follow-up patients younger than 18 years seen weekly for each provider group.

## RESULTS

### **Response Rate**

Of the 589 surveys mailed, 313 (53%) were completed and returned to us. Seventy-nine of the 313 respondents were ineligible because they were retired (31), not rheumatologists (7), not currently in patient care (22), currently in fellowship training (9), not physicians (2), or exclusively Veterans' Administration or correctional facility providers (8). In addition, review of ACR membership data and the California Medical Board Licensure Verification System ([www.docboard.org/ca/df/casearch.htm](http://www.docboard.org/ca/df/casearch.htm)) revealed that at least 49 nonrespondents were ineligible for the following reasons: retired (4), nonrheumatologist (1), not in patient care (13), currently in fellowship (3), not a physician (6), outside California (6), or bad address (16). Thus, our effective response rate (ie, number of eligible respondents divided by the number of eligible people in the sample) was 51%.

### **Comparison of Responders and Nonresponders**

Pediatric rheumatologists were significantly more likely than internist rheumatologists to respond to the survey (84% vs 49%;  $P = .001$ ). Among internist rheumatologists, however, response rates did not differ significantly between those who listed pediatric rheumatology as a secondary discipline and those who did not. Compared with physicians who practice in "other" settings, physicians whose primary practice location was a solo practice were somewhat less likely to respond to our survey (53% vs 44%;  $P =$

.093). ACR members who listed their primary discipline as internal medicine ( $n = 61$ ) were also less likely to respond than those who listed another primary discipline (34% vs 53%;  $P = .006$ ). Responders and nonresponders did not differ significantly in terms of their proximity to pediatric rheumatologists.

### **Characteristics of Pediatric Rheumatologists**

Selected characteristics of survey respondents are depicted in Table 1. Compared with all internist rheumatologists, pediatric rheumatologists are significantly less likely to be male and nonwhite. As expected, the overwhelming majority of pediatric rheumatologists described their exposure to pediatric rheumatology during fellowship as extensive. The few ( $n = 3$ ) who reported otherwise did related fellowships, such as allergy/immunology, but currently practice as pediatric rheumatologists.

In contrast to internist rheumatologists, pediatric rheumatologists were significantly more likely to be in academic rheumatology settings. A few pediatric rheumatologists reported being in an "other" setting; in most cases, these providers were in specialty clinics at children's hospitals. On average, pediatric rheumatologists spent significantly less time in rheumatology patient care and significantly more time in research and teaching than their internist rheumatologist counterparts. Compared with internist rheumatologists, pediatric rheumatologists saw significantly fewer patients per week. The patients of pediatric rheumatologists were significantly more likely to be covered by Medicaid than those of internist rheumatologists.

### **Comparison of Internist Rheumatologists**

Slightly more than one third of responding internist rheumatologists described themselves as treating pediatric rheumatology patients. Internist rheumatologists who treat children and those who do not treat children were comparable in terms of gender, age, race, board-certification status, number of years in practice, or hours worked per week. Compared with internist rheumatologists who do not treat children, those who treat children were more likely to report having extensive training in pediatric rheumatology during fellowship; however, this difference was not statistically significant. Internist rheumatologists who treat children practice significantly farther from a pediatric rheumatologist than those who chose not to treat children.

In logistic regression analyses, we found that internist rheumatologists who practiced between 10 and 50 miles from the closest pediatric rheumatologist were significantly more likely than those within 10 miles of a pediatric rheumatologist to treat children; the odds of treating pediatric patients among those who practice 50 or more miles from the nearest pediatric rheumatologist were nearly 7 times higher than among those who practice within 10 miles of a pediatric rheumatologist (Table 2). In addition, we found that internist rheumatologists who practice in multispecialty clinics were significantly more likely to be involved in the care of pediatric patients than

**TABLE 1.** Bivariate Comparison of Rheumatologists

	Pediatric Only ( <i>n</i> = 20; % or Mean [SD])	Unadjusted <i>P</i> Pediatric vs All Internists	Internists Involved In Care of Children ( <i>n</i> = 78; % or Mean [SD])	Internists Only ( <i>n</i> = 134; % or Mean [SD])	Unadjusted <i>P</i> Value* Internists Who Treat Children vs Internists Only
Personal characteristics					
Male	50.0	.04	67.6	75.2	NS
Age	49.3 (7.6)	NS	50.7 (9.2)	51.5 (11.3)	NS
Nonwhite	5.0	.05	21.3	25.8	NS
Years in practice	16.0 (8.7)	NS	17.2 (9.3)	17.9 (11.1)	NS
Training characteristics					
Exposure to pediatrics during fellowship					
None	5.3	N/A	17.8	24.6	NS
Minimal	5.3		48.0	40.2	
Moderate	5.3		26.0	31.2	
Extensive	84.2		8.2	4.1	
Practice characteristics					
Practice setting					
Private practice	15.0	<.001	53.3	52.3	.076
Academic rheumatology	50.0		14.7	22.0	
HMO	0.0		10.7	15.2	
Multispecialty clinic	15.0		20.0	7.6	
Other	20.0		1.3	3.0	
Percentage of time in professional activities					
Rheumatology care	58.3 (30.6)	.02	77.9 (25.4)	68.9 (30.9)	.07
Primary care	5.6 (21.3)	.08	5.1 (12.7)	9.2 (19.1)	NS
Research	14.9 (20.3)	<.001	7.2 (18.6)	9.2 (21.4)	NS
Teaching	12.7 (20.1)	<.001	3.8 (6.6)	3.7 (5.9)	NS
Other	8.4 (8.3)	.06	5.9 (10.8)	8.9 (16.5)	NS
Patients' insurance status					
Medicaid	37.5 (25.1)	<.001	8.2 (10.9)	11.5 (16.1)	NS
Private insurance	48.2 (22.5)	NS	49.8 (21.7)	44.9 (24.6)	NS
Medicare	7.3 (16.5)	<.001	34.0 (16.3)	34.4 (18.4)	NS
Self-pay/uninsured	5.2 (6.3)	NS	5.7 (8.7)	5.7 (10.8)	NS
Other	3.3 (11.5)	NS	4.9 (18.5)	9.7 (27.0)	NS
Hours worked per week	47.6 (19.8)	NS	48.6 (15.7)	49.2 (16.4)	NS
Total patients seen per week	34.5 (23.4)	<.001	76.6 (42.2)	67.1 (44.0)	NS
Patients <18 seen per week	27.5 (18.0)	<.001	3.1 (3.6)	1.7 (5.2)	<.001
Able to see more patients	35.0	NS	26.7	36.1	NS
Miles to nearest pediatric rheumatologist	N/A		30.2 (34.8)	15.3 (18.0)	<.001

SD indicates standard deviation; NS, not significant; HMO, health maintenance organization.

\* For dichotomous variables, statistical tests were performed using  $\chi^2$  when all cell sizes were >5. When  $\geq 1$  cells were <5, a 2-sided Fisher exact test was used. For continuous variables, 2-sided *t* tests were performed without assuming equal variances. For nonnormally distributed variables (Shapiro-Wilks test *P* < .05), Wilcoxon rank sum tests were used.

**TABLE 2.** Logistic Regression Results; Likelihood That an Internist Rheumatologist Treats Children

Independent Variable	Odds Ratio	<i>P</i>	95% CI	
Male	0.65	NS	0.32	1.32
Extensive experience in fellowship	2.07	NS	0.51	8.36
Practice location				
Academic rheumatology	1.12	NS	0.34	3.71
HMO	0.92	NS	0.33	2.57
Multispecialty clinic	3.39	.022	1.19	9.67
Other	0.75	NS	0.07	8.21
Percentage of time in nonpatient care	0.40	NS	0.07	2.27
Has more time available to see patients	0.79	NS	0.37	1.70
Distance to pediatric rheumatologist				
10–49 mi	2.06	.038	1.04	4.06
$\geq 50$ mi	6.84	.002	2.06	22.65

CI indicates confidence interval.

those who practice in private practice. It is interesting that when queried about their reasons for treating pediatric patients, 46.2% of those in multispe-

cialty practices cited insurance barriers to referral as a reason versus only 28.8% of those in other practice settings. Although this difference was not significant, our study was underpowered for this particular comparison.

We asked respondents about the extent to which various groups had contacted them to treat children with rheumatic diseases. The question was phrased as follows: "Have persons from the following groups contacted you about treating a pediatric patient with a suspected or diagnosed rheumatic condition?" More than 80% of internist rheumatologists who are involved in the care of children reported receiving being contacted by pediatricians (Fig 1). It is interesting that even internist rheumatologists who do not treat children reported being approached to treat children by many of the groups listed.

#### Comparison of Pediatric Rheumatologist and Internist Rheumatologists Who Treat Children

On average, pediatric patients represented a small percentage of internist rheumatologists' patients:

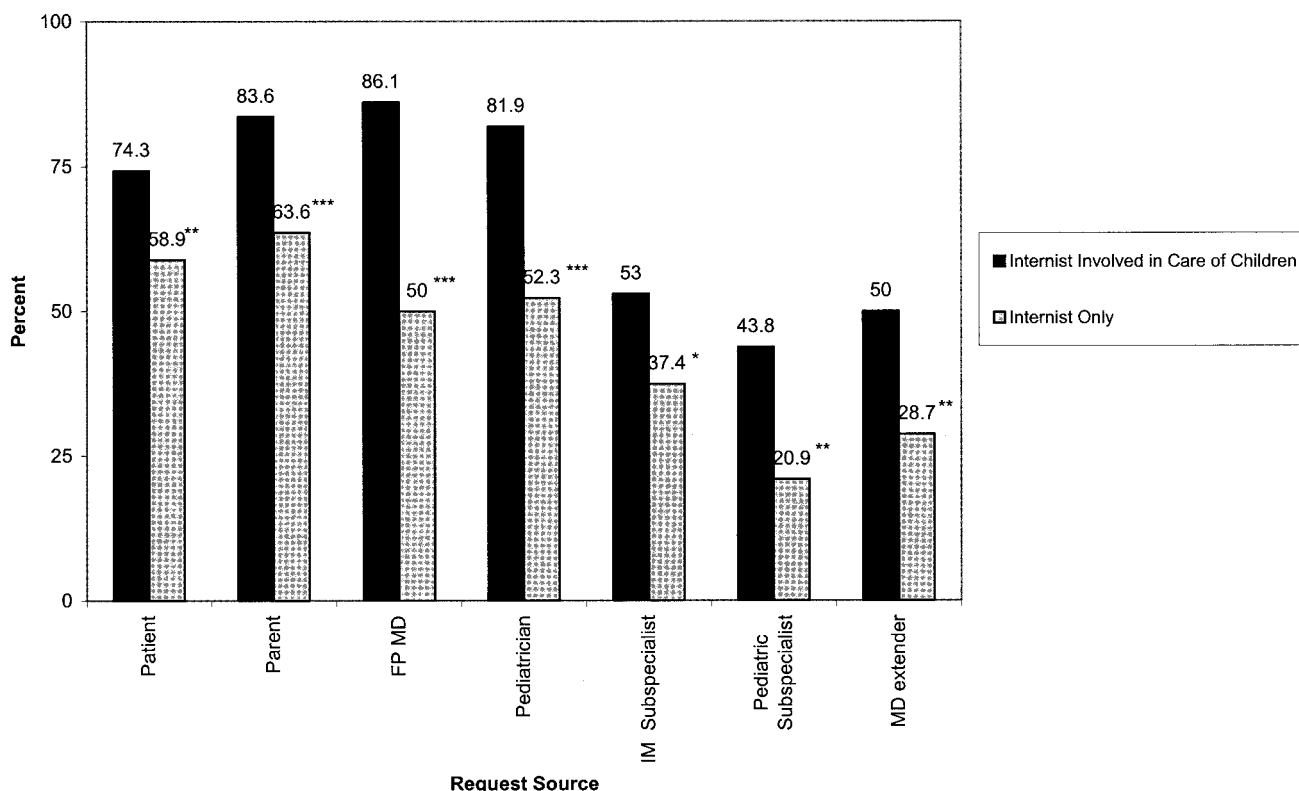


Fig 1. Percentage of internist rheumatologists who report being asked to see a pediatric patient by requesting source.

among internist rheumatologists who treat children, ~3% of their patients are younger than 18 years. Table 3 presents comparisons of pediatric rheumatologists and internist rheumatologists who are involved in the care of children. For highly skewed age and disease variables, we presented the median rather than the mean. All respondents who reported treating pediatric patients were asked to indicate the age and disease distribution of their pediatric patients. Internist rheumatologists were significantly less likely to treat children aged 0 to 5 and 6 to 11 than pediatric rheumatologists. On average, patients aged 16 to 17 represent >50% of internist rheumatologists' pediatric patients. For both pediatric and internist rheumatologist, the majority of patients had JRA or systemic lupus erythematosus.

Compared with pediatric rheumatologists, significantly fewer internist rheumatologists were comfortable with treating each condition. The majority of internist rheumatologists were comfortable with treating the JRA subtypes, systemic lupus erythematosus, dermatomyositis, and spondyloarthropathy; however, fewer than half of the responding internist rheumatologists who treat children were comfortable with treating Kawasaki disease, Wegener's granulomatosis, polyarteritis nodosa, reflex sympathetic dystrophy, psychogenic rheumatism, and fever of unknown origin.

#### Factors That Influence Internist Rheumatologists' Involvement in the Care of Children

Among internist rheumatologists who treat children, 79% indicated that personal expertise in pedi-

atric rheumatology motivated them to treat children. Patient preferences and distance to the nearest pediatric rheumatologist were also selected by 73.3% and 65.8% of internist rheumatologists who treat children, respectively. Among internist rheumatologists who do not treat children, the overwhelming majority (85.2%) refrain from seeing children because of inadequate personal expertise in pediatric rheumatology. Most internist rheumatologists (70.3%) also cite the availability of pediatric rheumatology care nearby as a reason for their decision not to treat children with rheumatic diseases.

#### Number of Patients Seen by Provider Group

On the basis of providers' self-reports of the number of patients younger than 18 years whom they treat weekly, we estimated that pediatric rheumatologists treated 550 patients under 18 per week. As a group, internist rheumatologists who treat children saw a total of 217 patients per week under 18. In addition, many internist rheumatologists who reported not treating pediatric patients did report treating patients younger than 18 years. As a group, these providers treat ~202 patients younger than 18 years in a week. In sensitivity analyses in which the number of children seen was coded to the lower end of reported ranges or to 0 when "<1" was reported, the number of children seen by pediatric rheumatologists was 468 weekly. Among internist rheumatologists who treat children and those who do not, the total number of patients younger than 18 years reported was 174 and 165, respectively.

**TABLE 3.** Comparison of Pediatric and Internist Providers of Pediatric Rheumatology Care

	Pediatric Rheumatologists Only (n = 20)	Internists Involved in Care of Children (n = 78)	Unadjusted P Value* Pediatric vs Internists Who Treat Children
Age distribution			
0–5 y	20.0	0.0	<.001
6–11 y	30.0	4.5	<.001
12–15 y	32.5 (9.84)	33.6 (22.59)	NS
16–17 y	16.4 (9.77)	52.4 (27.73)	<.001
Disease distribution among pediatric patients			
JRA	41.5 (17.5)	44.1 (31.3)	NS
SLE	19.3 (13.6)	23.0 (25.7)	NS
Pain syndromes†	7.5	1.0	NS
Other rheumatic disease†	11.5	5.0	NS
Rheumatic compliant with no diagnosis†	5.0	0.0	NS
Comfortable treating			
Dermatomyositis	95.0	56.2	.001
JRA, systemic onset	95.0	67.1	.01
JRA, pauciarticular	100.0	80.8	.04
JRA, polyarticular	100.0	80.8	.04
Fibromyalgia	100.0	64.4	.002
Kawasaki disease	100.0	24.7	<.001
Polyarteritis Nodosa	85.0	43.8	.001
Psoratic arthritis	90.0	80.8	NS
Reflex sympathetic dystropy	90.0	34.3	<.001
Rheumatic fever	100.0	49.3	<.001
Psychogenic rheumatism	90.0	30.1	<.001
Anterior knee syndrome	85.0	50.7	.005
SLE	95.0	72.6	<.001
Spondylarthropathy	100.0	79.5	.02
Wegener's granulomatosis	85.0	42.5	.001
Henoch-Schonlein purpura	100.0	61.6	.001
Fever of unknown origin	100.0	28.8	<.001
Back pain	85.0	60.3	.06
Reason for treating			
Personal expertise	N/A	78.4	N/A
Patient preference	N/A	73.6	N/A
Distance to nearest pediatric rheumatologist	N/A	65.8	N/A
Lack of available appointment	N/A	38.4	N/A
Inability to refer because of insurance	N/A	31.9	N/A
Practice income considerations	N/A	4.4	N/A
Other	N/A	42.1	N/A
Interested in obtaining advice from pediatric rheumatologist	N/A	71.4	N/A

SLE indicates systemic lupus erythematosus.

\* For dichotomous variables, statistical tests were performed using  $\chi^2$  when all cell sizes were  $>5$ . When  $\geq 1$  cells were  $<5$ , a 2-sided Fisher exact test was used. For continuous variables, 2-sided *t* tests were performed without assuming equal variances. For nonnormally distributed variables (Shapiro-Wilks test  $< .05$ ), Wilcoxon rank sum tests were used.

† Medians are presented for variables with highly skewed distributions for one or both groups.

## DISCUSSION

Access to pediatric rheumatology care may be constrained for a variety of reasons. Pediatric rheumatologists are few in number and geographically concentrated.<sup>3</sup> Of the 20 pediatric rheumatologists who answered our survey and were involved in patient care, 16 were located in the Los Angeles, San Diego, and San Francisco/San Jose areas. Furthermore, pediatric rheumatologists are significantly more involved in research and teaching and spend a smaller percentage of their time in patient care than their internist peers. Thus, even when a pediatric rheumatologist is geographically accessible, their availability for patient care may be constrained.

Internist rheumatologists who are involved in the care of pediatric patients were comparable to those who do not treat children, with a few notable exceptions. We found that internist rheumatologists who treat children practice significantly farther from pedi-

atric rheumatologists than those who do not treat pediatric patients. Internist rheumatologists who practice  $>50$  miles from a pediatric rheumatologist had significantly higher odds of treating pediatric patients than those who live within 10 miles of a pediatric rheumatologist. These results, which are consistent with those of Sherry et al,<sup>4</sup> suggest that internist rheumatologists who treat children act as substitutes for distant pediatric rheumatologists. In addition, internist rheumatologists who practice in multispecialty clinics were significantly more likely to treat children than those in private practice, controlling for selected other characteristics. It is possible that physicians in these types of groups may be more involved in independent practice associations. Independent practice associations may be less likely to include pediatric subspecialists and face disincentives to referring outside their network of providers.<sup>13,14</sup> This might explain the somewhat increased

tendency to report insurance barriers as a motivating reason for treating children among those in multi-specialty settings.

One particularly interesting finding is the high proportion of internist rheumatologists who report being contacted to see pediatric patients. Compared with internist rheumatologists who do not treat children, internist rheumatologists who treat children were significantly more likely to be contacted by all listed sources. It is not clear whether internist rheumatologists decide to treat children because they are asked to do so or providers have a reputation for treating children and, as a consequence, are approached more frequently to do so. It is also notable that internist rheumatologists who do not treat children frequently reported being contacted about seeing a pediatric patient with a known or suspected rheumatic condition.

More than 50% of internist rheumatologists who are involved in the care of children in our study reported having no or minimal exposure to pediatric rheumatology during their fellowship training. Although the percentage of internist providers who reported extensive exposure to pediatric rheumatology during fellowship was twice as high among those who see children, the percentages were very small (8% vs 4%) and we had insufficient power to test this comparison. A previous study found that >60% of Washington internist rheumatologists who treat children reported having moderate to extensive pediatric rheumatology experience during their fellowship, but only 20% of internist rheumatologists who do not treat children characterized their level of exposure to pediatric rheumatology during their fellowship as moderate or extensive.<sup>4</sup>

The distribution of pediatric patients across diseases did not differ significantly between pediatric rheumatologists and internist rheumatologists who treat children; however, there were considerable differences in the age distribution of their pediatric patients. Approximately one half of pediatric patients who were treated by internist rheumatologists were 16 and 17 years of age. Qualitative data from our survey also suggested that many internist rheumatologists who are involved in the care of children limited their pediatric practice to adolescents. In addition, a number of internist rheumatologists who did not report treating pediatric patients did indicate that they see patients younger than 18 years and see nearly as many patients younger than 18 as do internist rheumatologists who described themselves as treating children. These findings suggest that these providers may perceive adolescents differently from younger pediatric patients and may be a source of care for adolescents with rheumatic disease but be less available for younger children. Given the limited experience of these providers to pediatric patients during fellowship training, this self-restriction to older patients may be wholly appropriate. Caring for adolescents with chronic and potentially life-threatening rheumatic diseases, however, also poses unique psychosocial challenges that may benefit from pediatric or adolescent medicine input.

Although our response rate of 51% is certainly less

than ideal, it is typical of physician surveys.<sup>15</sup> One potential concern with our low response rate is that it may influence our estimates of the number of children who are treated by each provider group. Of the 4 pediatric rheumatologists who did not respond, 1 was semiretired and another was primarily a researcher. Because of this, we expect that our estimate of the number of children who are treated weekly by pediatric rheumatologists was only slightly underestimated. The accuracy of our estimates of the number of children who are seen by the 2 groups of internist rheumatologists are less clear, however.

Because this study was limited to California physicians, the applicability of these findings to other areas of the United States is limited. Approximately 12% of all board-certified pediatric rheumatologists in the United States practice in California.<sup>2</sup> Although California pediatric rheumatologists are concentrated in a small number of geographic areas, they are dispersed in such a way that we estimate that no internist rheumatologist was >200 miles from the nearest pediatric rheumatologist. Our findings might have been different had we performed our analysis in 1 of the 15 states in the United States with no board-certified pediatric rheumatologist. A national level survey of rheumatology providers' involvement in the care of children would give a better view of the role of internist rheumatologists in the care of children nationwide.

Finally, our study did not allow us to investigate the role of general pediatricians and family practitioners in caring for children with rheumatic diseases. In addition, we were not able to investigate the role of combined internal medicine and pediatric residency training on providers' willingness to be involved in the care of children.

#### Potential Solutions

From our findings and those of past studies, it is clear that the number and distribution of pediatric rheumatologists in the United States constrains the availability of their services for children with rheumatic diseases. Although a substantial minority of California internist rheumatologists reported that they are involved in the care of children, as a group, their pediatric patients are fairly limited to adolescents. Thus, for children who are younger than 12 years and have rheumatic diseases, especially those who live distant from academic medical centers, care may be difficult to obtain.

Whenever there are concerns about the availability of physician services, a selected number of potential solutions are debated. One possible solution to the current supply of pediatric rheumatologists is to increase the supply. At present, the Pediatric Rheumatology Section of the AAP is urging an increase in the number of pediatric rheumatologists in the United States to 400.<sup>16</sup> Increases in supply will be helpful only to the extent that new pediatric rheumatologists locate in medical schools and geographic areas that currently lack pediatric rheumatologists and have sufficient patient demand to support their services. Furthermore, their availability to provide patient care must be sufficient to allow timely receipt of care.

Finally, it is not clear that the goal of increasing the number of pediatric rheumatologists is achievable, as pediatric rheumatology fellowship programs do not fill their placements every year and rely on international medical graduates to fill many positions.<sup>17</sup>

Another potential solution is to increase the ability of internist rheumatologists to treat children. The American College of Rheumatology Guidelines on the Referral of Children With Rheumatic Diseases acknowledges the capacity constraints that the pediatric rheumatology workforce faces and recognizes the value of internist rheumatologists as providers of pediatric rheumatology care.<sup>18</sup> Currently, internist rheumatology fellowship training guidelines recommend but do not require the inclusion of training in pediatric rheumatology<sup>19</sup>; consequently, many internist rheumatologists may lack sufficient exposure to clinical pediatric rheumatology during their training to provide such care in their practices. Enhancement of fellowship training may enhance the ability of these providers to treat pediatric patients.

Another potential means of increasing access to quality rheumatologic care for children is facilitated collaboration between internist rheumatologists or general pediatricians and pediatric rheumatologists through telemedicine or other means of telecommunication. Such collaboration provides opportunities for ongoing education, selective referral of difficult cases, and increased access to clinical trials and emerging treatments. Among the internist rheumatologists who are involved in the care of children in our survey, more than three quarters indicated interest in obtaining advice from a pediatric rheumatologist via telemedicine or videoconferencing. Slightly more than one quarter of internist rheumatologists who do not treat pediatric patients indicated that the ability to obtain advice from a pediatric rheumatologist via telecommunications would influence their willingness to treat pediatric patients.

Finally, the role for general pediatricians and/or physician extenders in increasing access to care for children with rheumatic diseases remains unknown. Past studies have shown that children with swollen joints are frequently referred to orthopedic surgeons before being referred to pediatric rheumatologists.<sup>20</sup> This finding suggests that general pediatricians may have difficulties identifying and treating children with rheumatic complaints and/or lack local providers to treat such children. The Rheumatology Section of the AAP sponsors sessions related to the care of children with rheumatic diseases at the annual meeting of the AAP. The success of these programs in encouraging the involvement of general pediatricians in the care of children with these diseases has not been established. More research is needed to understand the role of general pediatricians in the diagnosis and treatment of children with rheumatic diseases.

### CONCLUSIONS

As one of the smallest pediatric subspecialties, pediatric rheumatology may offer an excellent "case study" of the implications of the current size and distribution of the pediatric subspecialty workforce

for patients who need these services. Much research is needed to determine the adequacy of the pediatric subspecialty workforce; the role of general pediatricians, internist subspecialists, and physician extenders in substituting for pediatric subspecialists; the relative quality of these various providers; and the implications for patient outcomes.

Assessments of the pediatric rheumatology workforce clearly should include the voices of internist rheumatologists. In this study, we have shown that internist rheumatologists in California, a state with a large number of pediatric rheumatologists, already function as a source of care for adolescents and, to a lesser extent, children with rheumatic diseases. On the basis of provider self report, we estimate that internist rheumatologists in California treat >40% of patients younger than 18 years seen weekly. It is plausible that the role of internist rheumatologists in states that lack pediatric rheumatologists is far greater. Furthermore, we know nothing about the role of the general pediatricians in treating children with rheumatic diseases.

The prominent role of internist rheumatologists in the care of children with rheumatic diseases begs the question, "Do we have enough pediatric rheumatologists in the United States?" The answer is not simple. Clearly, internist rheumatologists are substituting for the less available care of pediatric rheumatologists; however, given the relative rarity of these conditions, care must be taken in increasing numbers beyond what could be supported by patient care, teaching, and research demands. At a minimum, however, the 45 medical schools<sup>21</sup> that currently lack a pediatric rheumatologist on the faculty would benefit significantly from the presence of a pediatric rheumatologist for resident and fellowship training programs in pediatrics, internal medicine rheumatology, and orthopedics in addition to providing subspecialty care for affected patients.

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### REFERENCES

1. Corridan K. What is your pediatrician worried about? *Child.* 2002;Nov: 118–121
2. American Board of Medical Specialties. Geographic Distribution of Diplomats by Subspecialty Certificate. Available at: [www.abms.org/Downloads/Statistics/Table\\_8\\_2003.PDF](http://www.abms.org/Downloads/Statistics/Table_8_2003.PDF). Accessed October 14, 2003
3. Mayer ML, Sandborg CI, Mellins ED. Access to pediatric rheumatology care in the United States. *Arthritis Care Res.* 2003;49:759–765
4. Sherry DD, Wallace CA, Kahn SJ. Pediatric rheumatology in adult rheumatology practices in Washington state. *Arthritis Rheum.* 1996;39: 1218–1221
5. Giannini EH, Ruperto N, Athreya B, Cassidy JT, White P. Specialty training and distribution of work effort among US American College of Rheumatology members caring for children with rheumatic disease. *Arthritis Rheum.* 1997;40:2273–2274
6. Kuhlthau K, Ferris TG, Beal AC, Gortmaker SL, Perrin JM. Who cares for Medicaid-enrolled children with chronic conditions? *Pediatrics.* 2001; 108:906–912
7. The future status of pediatric rheumatology in the United States: strategic planning for the year 2000. American College of Rheumatology Blue Ribbon Committee for Academic Pediatric Rheumatology. *Arthritis Rheum.* 2000;43:239–242
8. American College of Rheumatology. Juvenile Arthritis. Available at:



- www.rheumatology.org/patients/factsheet/jra.html. Accessed June 12, 2002
9. Rich RR, Herion JC, Palmer JG, eds. *Clinical Immunology: Principles and Practice*. 2nd ed. London, UK: Mosby; 2001
  10. Newacheck PW, Halfon N, Budetti PP. Prevalence of activity limiting chronic conditions among children based on household interviews. *J Chron Dis*. 1986;39:63-71
  11. Gortmaker SL, Sappenfield W. Chronic childhood disorders: prevalence and impact. *Pediatr Clin North Am*. 1984;31:3-18
  12. Bureau of Health Professions. *Area Resource File*. Fairfax, VA; Quality Resource Systems, Inc; 2002
  13. Schaffler HH, McMenamin S, Cubanski J, Hanley HS. Differences in the kinds of problems consumers report in staff/group health maintenance organizations, independent practice association/network health maintenance organizations, and preferred provider organizations in California. *Med Care*. 2001;39:15-25
  14. Grembowski DE, Cook K, Patrick DL, Roussel AE. Managed care and physician referral. *Med Care Res Rev*. 1998;55:3-31
  15. Cummings SM, Savitz LA, Konrad TR. Reported response rates to mailed physician questionnaires. *Health Serv Res*. 2001;35:1347-1355
  16. Spencer C. Chairperson's Corner. American Academy of Pediatrics Section on Rheumatology. Available at: [www.aap.org/sections/Rheumatology/SORhspring02.pdf](http://www.aap.org/sections/Rheumatology/SORhspring02.pdf). Accessed July 1, 2003
  17. Ostrov B. Development of a New Pediatric Rheumatology Program. American Academy of Pediatrics Section on Rheumatology. Available at: [www.aap.org/sections/Rheumatology/SORhwinter03.pdf](http://www.aap.org/sections/Rheumatology/SORhwinter03.pdf). Accessed July 1, 2003
  18. Sandborg CI, Wallace CA. Position statement of the American College of Rheumatology regarding referral of children and adolescents to pediatric rheumatologists. Executive Committee of the American College of Rheumatology Pediatric Section. *Arthritis Care Res*. 1999;12:48-51
  19. Accreditation Council on Graduate Medical Education. Program Requirements for Residency Education in Rheumatology. Available at: [www.acgme.org/req/150pr799.asp](http://www.acgme.org/req/150pr799.asp). Accessed January 14, 2002
  20. Cuesta IA, Kerr K, Simpson P, Jarvis JN. Subspecialty referrals for pauciarticular juvenile rheumatoid arthritis. *Arch Pediatr Adolesc Med*. 2000;154:122-125
  21. Cassidy JT, Athreya B. Pediatric rheumatology: status of the subspecialty in United States medical schools. *Arthritis Rheum*. 1997;40:1182

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